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CHAPTER 4

Benefits of a combined community-based dementia support programme compared to traditional respite care on carer needs, emotional burden and quality of life

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Abstract

Objectives

Within an implementation study, we investigated the effectiveness of a combined community-based (CO) day care program for persons with dementia and their carers versus traditional psychogeriatric nursing home-based (NH) day care. The effects on needs, sense of competence, burden, and quality of life of the family carers were studied.

Methods

A pretest-posttest control group design among family carers of people with dementia who joined CO day care centres (n = 67) or NH day care centres (n = 64).

Results

After six months, family carers using CO day care more often expressed an unmet need for support regarding psychological distress than carers utilizing NH day care. Carers with a low sense of competence using CO compared to NH day care became less emotionally burdened by behaviour and mood problems of their relative.

Discussion

The results indicate an added value of CO day, and a larger controlled follow-up study is recommended to understand the long-term effects of CO day care over NH day care.

Introduction

In 2013 in the Netherlands, about 300,000 family carers cared for about 260,000 people with dementia (Van den Berg *et al.*, 2014). Family carers play an important role in the care for community-dwelling people with dementia: on average they care for their relatives 20 hours a week during five years. As a result of this caregiving role, and in particular the experienced difficulties in dealing with neuropsychiatric symptoms of the person with dementia, negative side effects occur frequently: 70% of family carers feel burdened and almost 20% feel overburdened (Peeters *et al.*, 2012). High levels of strain, anxiety and depression are reported by dementia carers across countries in the last decades (Brodaty *et al.*, 2003; Cooper *et al.*, 2012; Pot *et al.*, 2000; Schulz *et al.*, 1995).

Many psychosocial interventions are available for people with dementia and family carers to support them in coping with the consequences of dementia and to improve their quality of life. Interventions targeted at supporting both the person with dementia and the family carer are 'combined interventions'. These combined interventions appear to be more effective than single interventions (Olazaran *et al.*, 2010; Smits *et al.*, 2007; Van 't Leven *et al.*, 2013). Examples are a Tailored Activity Program (Gitlin *et al.*, 2008), Community Occupational Therapy in Dementia (COTiD) (Graff *et al.*, 2007) and the Integrative Reactivation and Rehabilitation Program (IRR; Bakker *et al.*, 2011), with effects found in the persons with dementia (e.g. on agitated behaviour, activities of daily life, depression and neuropsychiatric symptoms) and family carers (for example on sense of competence, burden and mastery).

Another effective combined intervention, widely provided in the Netherlands for more than 20 years, is the Meeting Centers Support Program (MCSP) for community-dwelling people with dementia and their family carers (Dröes *et al.*, 2009). These MCSPs are offered at easy-access locations such as community centres and aim to provide timely and attuned care that effectively supports community-dwelling people with dementia and their family carers in adapting to and coping with the consequences of dementia (Dröes *et al.*, 2000; Dröes *et al.*, 2004). Repeated multi-centre studies into the effectiveness of the MCSP have shown that Meeting Centers are more (cost-) effective than traditional nursing home-based psychogeriatric day care centres that do not offer a carer support programme (from now: NH day care centres). After six months of participation, persons with dementia had less behaviour and mood problems and better self-esteem. Their carers felt less burdened and more competent to care for their relative. Furthermore, there were strong indications of delayed nursing home admission, and the participants (people with dementia as well as carers) were highly satisfied with the support programme in the Meeting Centers (Dröes *et al.*, 2000; 2004; 2006; 2011).

Despite this evidence, very few NH day care centres adopted the combined MCSP model. To stimulate further dissemination an implementation study was started in 2011 to gain insight into the conditions of successful transition of NH day care centres to community day care centres

with carer support (from now on named: 'CO day care'), and potential differences in outcomes and costs of the two types of psychogeriatric day care. Six NH day care centres made the transition to CO day care centre. This transition meant, among other things, moving to an easy-access building in the community, offering day care in an open setting based on the principles of the adaptation-coping model (this means assisting participants to deal with the consequences of dementia), starting a support programme for carers who can freely make use of it if they have a need, training staff, and integrating psychomotor therapy and other therapeutic activities in the daily routine of the CO day care centre. We recently reported on the conditions for successful transition to CO day care (Van Haeften-van Dijk *et al.*, 2015). We also explored the effects of *newly developed* and *longer existing* CO day care versus NH day care on people with dementia. We found indications that in *new* CO day care centres people with dementia had less neuropsychiatric symptoms, and in *longer existing* CO day care centres they had less care needs compared to participants of NH day care (Van Haeften-van Dijk *et al.*, 2016b). Participants and carers of CO day care were more satisfied with the day care atmosphere, location, contact with staff, the activities at the centre and the received support compared to participants of NH day care and their carers (Van Haeften-van Dijk *et al.*, 2016a). In this article we focus on the carers. We compared carers of persons with dementia in the CO day cares with carers of participants of the traditional NH day care centres to find out if the two types of day care had a different impact on the carers' needs, feelings of competence and burden.

Method

Study design

For this explorative evaluation, which was part of an implementation study, a pretest-posttest control group design with non-equivalent groups and three measurements (at zero, three and six months) was used. The experimental group consisted of dyads of people with dementia and their family carer, who received support from a CO day care. The control group consisted of dyads who received support in traditional NH day care. To investigate whether it made any difference if the transition was made recently or many years ago (meaning much more time to implement the intervention), *new* CO day care centres that recently made the transition as well as *longer existing* CO day care centres were included in the study.

Setting and participants

To enable detection of medium size effect (d = 0.5) in carers with a power of 0.80, alpha 0.05, and taking into account an expected drop-out rate of 15%, it was calculated that a total of 150 carers (75 experimental and 75 controls) was needed (Cohen, 1988). Six NH day care centres (control group) in the province North Holland of the Netherlands, made the transition to (new) CO day care (experimental group). Five longer existing CO day care centres were recruited in the south-east of the Netherlands. Five NH day care centres from the same region served as control group. Thus, a total of 11 CO day care centres and 11 NH day care centres participated in the study. The total number of included persons per day care centre varied from 1 to 23. New participants (people with dementia and their carers) were invited to take part in the research via an informed consent procedure (see Procedure). The only inclusion criterion for family carers was that they took care of a person with a diagnosis of some type of dementia. The experimental group (new or longer existing CO day care) consisted of 67 carers, the control group (NH day care) of 64 carers.

The interventions in experimental and control group

The support programme of CO day care is based on the combined Meeting Centres Support Programme for people with dementia and their carers. The target group of CO day care consists of community-dwelling people with mild to severe dementia and their carers. Care and support is offered in a community-based, socially integrated, easy access location. During various days a week the persons with dementia can participate in a personalized activity programme (including recreational and creative activities, music, reminiscence and psychomotor therapy). The carers are free to join the informative meetings about dementia-related topics (for example the diagnosis, dealing with behaviour changes and available professional care and support in the neighbourhood) and the ongoing discussion groups with peers if they feel the need for it. The day care for the person with dementia serves as respite care for the carers. In addition, both the persons with dementia and the carers can utilize a

consulting hour, receive case management, participate in social activities and outings, and in centre meetings where all parties involved (patients, family carers, volunteers and professionals) can exchange experiences and express their wishes concerning the support programme. The care and support in the CO day care centres are offered by a small fixed team consisting of a programme coordinator, activity therapists, care assistants and volunteers who are supervised and assisted by a psychologist or elderly care medicine specialist from the care organisation that the day care is linked to. The centres organize the support programme in cooperation with local care and welfare service providers in order to reduce fragmentation and improve integration of care. In the six CO day care centres that made the transition from NH day care during this study, it took some time before the full combined support programme was offered: the activity programme for persons with dementia (which also provides respite to family carers) started immediately, whereas support for the family carers started within one month after opening in three of the new CO day care centres, and after seven months in the other three centres. After the transition, there was more emphasis on cooperation between staff and family carers, which was reflected by more frequent contact by telephone and/or during centre meetings and discussion groups (see also Van Haeften-van Dijk *et al.*, 2015).

The traditional NH day care centres are located in specialized units of the nursing home. The target group consists of community-dwelling people with mild to severe dementia. They offer social activities and psychosocial interventions such as reminiscence and activity therapy for the persons with dementia. Treatment is offered by multidisciplinary teams consisting of the social, psychological, paramedical and medical discipline. Compared to the CO day care, the support programme for family carers is much less intensive and structured: often there are only incidental contacts with family carers, and one or two informative family meetings a year. Few NH day care centres offer discussion groups with peer carers. For a full overview of the differences between the MCSP and NH day care, please refer to Table 1.

Table 1. Description of nursing home-based day care (NH day care) versus community day care with carer support (CO day care)

	MCSP model	Before transition: NH day care	After transition: CO day care/ longer existing CO day care
Target group	PwD in mild to moderately severe stage + informal carers	PwD in moderate to severe stage. In some day care centres: Acquired brain injury/ psychiatric disorders	PwD in mild to severe stage + informal carers. In some day care centres: Acquired brain injury/ psychiatric disorders
Person with Dementia (PwD)			
Psychomotor therapy	Three days per week offered	Not offered (regularly)	Twice per week to daily
Recreational and creative activities	Specifically attuned to abilities and wishes of PwD	Fixed day care programme more or less attuned to abilities and wishes of PwD	Varying from more or less to specifically attuned to abilities and wishes of PwD
Informal carer			
Discussion groups with peers	Ongoing discussion groups for carers	Not offered regularly	Ongoing discussion groups for carers who want to participate (every 6-8 weeks)
Information	Monthly informative meetings and/ or joint monthly Alzheimer café visit	Not offered regularly	Half-yearly to monthly informative meetings and/ or joint monthly Alzheimer café visit
For both PwD and carer			
Evaluation of support programme and activities with PwD and their carers	Monthly/ 3 monthly 'centre meetings'	Not regularly	Varying from not organized (yet) to every three-six months a 'centre meeting'
Consultation hour	Weekly consultation hour with programme coordinator	Irregular individual contact with informal caregivers	Varying from regular individual contact with informal caregiver to weekly consultation hour
Social activities with all participants (PwD and informal carer)	Frequency and type of activities discussed during 'centre meeting'	Rarely organized	Frequency and type of activities discussed during 'centre meeting'
Staff			
Professional caregivers	Trained in and working according to adaptation-coping model	Not trained in adaptation-coping model	Trained in adaptation-coping model
Volunteers	Structurally present	None / few	Varying from absent to structurally present
General			
Care philosophy	Individual care plan based on adaptation-coping model. Care strategy is based on a psychosocial diagnosis regarding adaption to/ coping with dementia	Individual care plan focused on actions to be taken in the physical, environmental, participation and mental domains to improve wellbeing.	Limited to total embedding of adaptation-coping model in care plans of persons with dementia and carers
Location	Community building	Nursing home	Community building / ground floor of flat / next to shopping centre / community restaurant
Social integration	Regular activities with children, youth, other neighbours	Regular activities with nursing home residents, occasionally with children, youth, other neighbours	Regular activities with children, youth, other neighbours
Cooperation written down in cooperation protocol and signed by the most relevant organisations	Signed cooperation protocol by relevant organisations	Cooperation with 2-4 organisations, no formal cooperation protocol or agreement	Signed cooperation protocol by 5-6 relevant organisations

Measuring instruments

Background characteristics

Socio-demographic characteristics of persons with dementia and family carers were collected at the first interview with the family carer. Information on the diagnosis was collected via the coordinator of the day care centres or the general practitioner. The severity of cognitive impairments of the person with dementia was assessed with the Mini Mental State Examination (MMSE; range 0-30) (Folstein *et al.*, 1975); the number of behaviour and mood problems with the NeuroPsychiatric Inventory (NPI, range 0-12; Cummings *et al.*, 1994; de Jonghe *et al.*, 2003a).

Carers' use of the support programme of CO day care

Family carers' use of and subjective experiences with the support programme were assessed by means of a survey, sent after six months participation. The survey addressed, among other things, the satisfaction with staff involvement (e.g. 'care staff listens to my opinion sufficiently'), the opinion on the overall atmosphere in the centre (e.g. 'the day care is atmospheric') and carers' involvement in the day care and/or carer programme and satisfaction with specific elements of the support programme (e.g. 'Did you take part in the discussion group with peers?' and 'How would you rate the frequency of the group meetings?').

Primary outcomes

The primary family carer outcomes were support needs and sense of competence. Support needs of the carer were measured by two items of the Camberwell Assessment of Need for the Elderly (CANE; Dröes *et al.*, 2004; Reynolds *et al.*, 2000): Besides care needs of the elderly, this instrument comprises two needs sections for the carer, one with regard to information and one on psychological distress (test-retest reliability of kappa = 0.40 and kappa = 0.70 respectively) (Van der Roest *et al.*, 2008). The sense of competence of family carers was measured with the Short Sense of Competence questionnaire (SSCQ, kappa = 0.76, range 0-7; Vernooij-Dassen *et al.*, 1999). The SSCQ is a seven-item questionnaire that assesses the degree to which family carers feel capable of caring for a person with dementia on a 5-point scale (that is dichotomized for the analyses, according to the instructions of the authors; Vernooij-Dassen *et al.*, 1999).

Secondary outcomes

The secondary outcomes were the emotional burden felt by the carer in relation to neuropsychiatric symptoms of the person with dementia, care-related quality of life, objective burden, subjective burden, and nursing home admission of the person with dementia.

Burden caused by neuropsychiatric symptoms in people with dementia was assessed using the emotional burden subscale of the Neuro Psychiatric Inventory (NPI, $\alpha = 0.88$, range 0-36; Cummings *et al.*, 1994; de Jonghe *et al.*, 2003b). For each of the twelve neuropsychiatric symptoms of the NPI carers were asked to indicate on a 6-point scale how emotionally

distressing the symptom was for them (from 'not emotionally distressing' to 'extremely distressing').

The CarerQoL-7d (Brouwer *et al.*, 2006) was used to measure care-related quality of life. The CarerQoL-7d measures subjective burden of caring on seven dimensions. A weighted sum score is calculated from these items with a range from 0 (negative caring situation) to 100 (positive caring situation; Hoefman *et al.*, 2014).

Objective burden was measured by asking carers how many hours per week they assisted the person with dementia in personal care, household, administrative support and going with them to doctor's appointments. Subjective burden was assessed by asking *'how burdensome is caring for your partner/mother/father/etc?*' on a range from 0 (not burdensome) to 10 (very burdensome).

Nursing home admission of the person with dementia was recorded and the percentage of participants being admitted to a nursing home after 6 months was calculated.

Procedure

The study was approved by the medical ethics committee of VU University Medical Centre. At the start of participation in one of the day care programmes the staff of the day care centre provided oral and written information on the study to the person with dementia and the carer and invited them to participate in the study. When the carer and the person with dementia indicated their interest in participating in the study, the researcher received contact details of the dyad and contacted them to explain the research in more detail. If they agreed to take part, both were invited to sign an informed consent form. Data were collected from August 2011 to March 2014. All but one of the interviewers (n = 20) were students (BSc or MSc) with experience in interviewing, either through their education or through (voluntary) work. All interviewers received half a day of training in how to administer the measuring instruments in this study, and were supervised by the researcher. After six months, carers received a questionnaire by mail about their use of, and satisfaction with the support programme offered in the CO or NH day care centre.

Data analysis

The data were analysed using SPSS 20.0. In case of missing values at baseline, caused by people not (yet) willing to participate when starting in the day care, or being referred too late to the researchers (after the first month of participation), the three-month measurement data were imputed for the baseline. These participants were also considered 'completers'. This procedure was based on results of previous studies of Dröes *et al.* (2000, 2004) that showed no statistically significant differences in outcomes between MCSP and NH day care within 3 months of participation. We therefore based our effect analysis on the data collected at baseline and after six months participation.

Descriptive analyses were performed on data of all participants and subgroups, including non-responders at the start of the study, and drop-outs during the study. To test for differences

between groups and attrition bias we used chi-square (χ^2) tests for nominal variables and Kruskal-Wallis and Mann-Whitney U tests for ordinal and interval variables. Characteristics on which the groups differed at baseline and which were related to the outcome measures, were included in the analyses as a potential confounder. Subsequently, we identified potential effect modifiers by assessing from literature which characteristics are expected to be related to our outcome measures, and we examined in SPSS if these characteristics of the person with dementia or the carer (e.g. severity of behaviour and mood problems of the person with dementia (NPI-Q) and carers' subjective health and sense of competence at baseline (SSCQ)) were indeed related to our outcome measures by including interaction terms in the univariate covariance analyses (ANCOVA). If the interaction term was significant on a $p< 0.05$ level, we treated the characteristic as effect modifier in the data analysis.
ANCOVA´s were carried out to compare outcome measures at T2 (after 6 months) in the experimental and control group, while the baseline data (T0) and potential confounding variables were included in the analysis as covariates. This strategy is recommended in small samples (Cohen J., 1988). In the same way we explored for differences between the *new* CO day care centres or the *longer existing* CO day care centres and the NH day care centres. In case of effect modification (see above), the results are presented separately for the different groups (e.g. low versus high sense of competence at T0. We used two-tailed tests with a significance level of five percent, and the Bonferroni correction to counteract the problem of multiple comparisons. To calculate the effect sizes of the outcomes we used Cohen's d (for ANCOVAs) and Cramer's V (for chi-square (χ^2) tests). Cohen's d was interpreted as small (0.20), medium (0.5) or large (≥0.80). Cramer's V was interpreted as small (0.10), medium (0.30) or large (≥0.50; Cohen, 1988). We used chi-square (χ^2) tests to examine statistical differences in nursing home admission between the groups. Correlations between nursing home admission and severity of dementia (dichotomized) and behaviour and mood problems (NPI-Q) at baseline, were examined using Spearman rank correlations.

Results

Study participants and drop-outs

Figure 1 displays a flowchart of the recruitment of study participants (n = 131), and the number and reasons for non-response and drop-out at the different time points of the study. For 22 persons the baseline measurements (T0) were missing because informed consent for the study was received too late, that is more than one month after the start of participating in day care. We found no significant differences between study participants and people not willing to participate on gender of the carer, his/her relation to the person with dementia, marital status or living situation (cohabiting with the person with dementia or not).

We also examined if drop-outs in the experimental (n = 30, 23%) and control groups (n = 29, 22%) differed significantly from the completers (n = 72) on background characteristics and outcome measures. We did not find any significant differences.

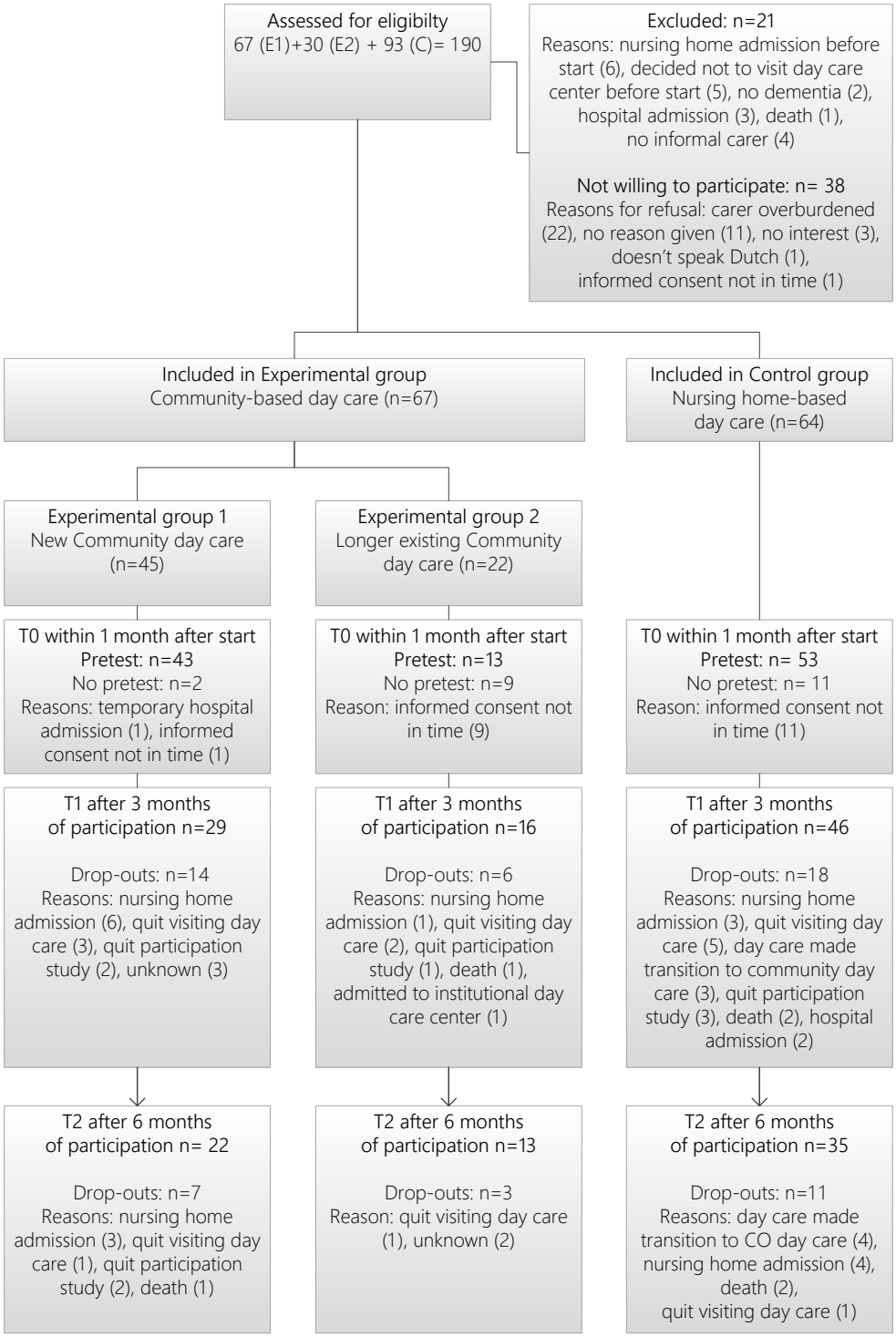

Figure 1. Flowchart of the study

Table 2. Socio-demographic characteristics of the study participants (informal carers of people with dementia)

	All respondents		Respondents with measurement at baseline and 6 months*		
	Group E: Community day care (n = 67)	Group C: Nursing home-based day care (n = 64)	Group E: Community day care (n = 37)	Group C: Nursing home-based day care (n = 35)	test statistic p-value
Female, n (%)	44 (67%)	43 (67%)	27 (75%)	21 (60%)	$\chi^2 = 1.8$ p = 0.18
Age, years (sd)	66.4 (13.5)	63.8 (13.8)	65.4 (11.3)	65.4 (12.9)	Z = -0.9 p = 0.93
Education, n (%)					$\chi^2 = 0.6$ p = 0.90
Primary school	12 (18%)	10 (17%)	7 (19%)	8 (23%)	
Low	27 (41%)	24 (39%)	12 (32%)	12 (35%)	
Middle-high	13 (20%)	14 (23%)	9 (24%)	8 (23%)	
High	14 (21%)	13 (21%)	9 (24%)	6 (18%)	
Relation to care receiver, n (%)					$\chi^2 = 2.9$ p = 0.40
Husband/ wife/ life partner	33 (49%)	30 (47%)	20 (54%)	16 (46%)	
Brother/sister (in law)	2 (3%)	0 (0%)	2 (5%)	0 (0%)	
Son/daughter	28 (42%)	32 (50%)	13 (35%)	17 (48%)	
Other	4 (6%)	2 (3%)	2 (5%)	2 (6%)	
Shared household with PwD, n (%)	38 (57%)	33 (52%)	23 (62%)	18 (51%)	$\chi^2 = 0.9$ p = 0.40
Marital status, n (%)					$\chi^2 = 1.5$ p = 0.70
Married/ living together	52 (82%)	56 (87%)	32 (87%)	31 (88%)	
Widowed/ Divorced/ Single	11 (18%)	8 (13%)	5 (13%)	4 (12%)	
Other activities besides care, n (%)	25 (38%)	29 (47%)	16 (43%)	15 (43%)	$\chi^2 = 0.0$ p = 1.00
Gainfully employed, n hrs per week (sd)	16 32.3 (13.0)	16 25.9 (8.2)	10 33.8 (14.0)	7 27.4 (8.8)	$\chi^2 = 0.4$ p = 0.50
Number of months informal caregiving, median [95% CI]	15.0 [12.2, 20.6]	18.0 [17.0, 27.9]	18.0 [12.4, 23.3]	16.0 [15.3, 32.5]	$\chi^2 = 0.6$ p = 0.50
MMSE-score PwD, range 0-30, mean (sd)	18.1 (7.3)	18.7 (5.0)	17.9 (8.1)	19.0 (4.8)	Z = -0.3 p = 0.80
Number of neuropsychiatric symptoms (NPI, range 0-12), mean, sd	5.4 (2.8)	5.3 (2.6)	5.2 (2.9)	5.1 (2.3)	Z = -0.1 p = 0.92

sd = standard deviation, χ^2 = Pearson Chi square, Z = z value Mann Whitney U test.

Carers' use of and satisfaction with the support programme of CO and NH day care

After six months of participation in the CO day care, 18 of the 35 carers (51%) of the experimental group returned the questionnaire about their participation in the support programme for carers. Of these carers, 67% (n = 12) indicated they participated in one or more components of the support programme for carers, e.g. the peer support groups, informative meetings, the consultation hour and/or the centre meeting. Non-participation of carers in the support services was accepted, because the carers in CO day care– apart from the respite care - are free to join any of the support activities or not (unlike the MCSP where carers are expected to utilize the carer support programme). Overall satisfaction with the support programme in both CO day care (mean = 8.1, sd = 0.9) and NH day care (n = 25, response = 71%, mean = 7.9, sd = 0.9) was high and did not differ between groups (F = 0.2, p = 0.66).

Results on outcome measures

Table 3 shows the results of the ANCOVAs on the outcome measures of the experimental and control group after six months. No significant differences were found between the groups on sense of competence (SSCQ) or need for information (CANE). Regarding psychological distress (CANE) we found an increase in expressed needs for support in the CO day care: participants in the CO day care group after six months reported more often having unmet needs and less often having no need for support compared to the control group ($\chi^2 = 7.7$, df = 2, p = 0.02, V = 0.3). Further explorative analyses showed that this occurs mainly in the newly developed CO day care centres ($\chi^2 = 9.9$, df = 2, p = 0.01, V = 0.4).

On the secondary outcomes care-related quality of life, objective burden and subjective burden, no significant differences were found between the groups.

For the outcome emotional burden (NPI) 'sense of competence' was an effect modifier. We therefore classified carers with a low (score 0-4, n = 26) and high (score 5-7, n = 43) sense of competence. The carers with a low sense of competence at baseline who participated in the experimental group reported lower emotional burden than carers in the control group (F = 7.4; p = 0.01; d = -1.1).

We further explored if potential effects differed for carers of persons with dementia who participated in the newly developed or the longer existing CO day care centres compared to the control group. However, we did not find significant differences in outcome measures between these groups (data not shown).

Table 3. Results (unclassified and classified) of the ANCOVA analyses on outcome measures in family carers between baseline measurement and after 6 months of participation in CO day care centres (Group E) and NH day cares centres (Group C)

			Pretest		6 months					
	N Group E	N Group C	Group E	Group C	Group E	Group C	χ2	p		Cramer's V
CANE										
Need for information	36	34					1.5	0.46		0.2
No need, n (%)			27 (75%)	22 (63%)	29 (81%)	23 (67%)				
Met need, n (%)			6 (17%)	8 (23%)	4 (11%)	6 (18%)				
Unmet need, n (%)			3 (8%)	5 (14%)	3 (8%)	5 (15%)				
Psychological distress	36	34					7.7	**0.02**		0.3
No need, n (%)			23 (62%)	18 (51%)	21 (58%)	23 (68%)				
Met need, n (%)			9 (24%)	12 (34%)	3 (8%)	8 (24%)				
Unmet need, n (%)			5 (14%)	5 (14%)	12 (33%)	3 (8%)				
			Pretest (a)		6 months (a)		Adj. means 6 months (b)			
	N Group E	N Group C	mE (sd)	mC (sd)	mE (sd)	mC (sd)	AdjmE (se)	AdjmC (se)	F	p	d
SSCQ										
Sense of competence (range 0-7)*, mean (SD)	33	30	5.1 (1.8)	5.2 (1.5)	5.4 (1.6)	5.1 (1.4)	5.4 (0.2)	5.1 (0.2)	1.8	0.18	0.3
NPI-Q										
Caregiver emotional burden (range 0-60)*, mean (SD)	36	34	11.9 (9.5)	11.5 (8.1)	11.4 (10.0)	12.3 (10.9)	11.2 (1.4)	12.5 (1.4)	0.4	0.51	-0.2
NPI-Q classified										
Caregiver emotional burden (range 0-60)*, mean (SD)										
SSCQ low	12	14	19.8 (9.4)	15.5 (6.8)	14.4 (10.1)	20.1 (11.8)	12.4 (2.5)	21.9 (2.3)	7.4	**0.01**	-1.1
SSCQ high	23	20	7.4 (6.3)	8.7 (7.9)	9.5 (9.9)	6.9 (5.8)	9.9 (1.5)	6.4 (1.6)	2.7	0.11	0.5
Minimal dataset (MDS)										
CarerQoL-7d (range 0-100)*	31	34	76.9 (17.6)	74.2 (17.7)	77.9 (16.0)	72.4 (15.2)	77.0 (1.9)	78.2 (1.8)	0.2	0.65	-0.1
Objective burden (hours of care/week)	33	30	32.5 (37.1)	23.5 (23.3)	34.1 (42.3)	25.2 (29.0)	34.0 (6.5)	25.3 (6.8)	0.9	0.36	0.2
Subjective burden (range 1-10)*	35	32	5.0 (2.7)	5.5 (2.5)	5.4 (2.6)	5.1 (2.7)	5.6 (0.4)	4.9 (0.4)	1.7	0.19	0.3
					6 months					
	N Group E	N Group C			mE (sd)	mC (sd)	χ2	p		Cramer's V
Nursing home admission after 6 months, n (%)	70	68			10 (14.3%)	8 (11.8%)	0.2	0.66		0.0

a. Unadjusted mean scores at baseline and at six months, b. Mean scores at six months are adjusted for baseline scores, * Underlined score is the most favourable, PwD = Person with dementia, mE = Mean score Experimental group, mC = Mean score Control group, sd = standard deviation, se = standard error, d = Cohen's d effect size (small = 0.20, medium = 0.50, large = ≥ 0.80), χ2 = Pearson chi square, SSCQ low = score between 0-4, SSCQ high = score between 5-7.

Next, we investigated if the changes over six months in need for support regarding psychological distress (CANE) were associated with the emotional burden of carers due to behavioural and psychological symptoms of the person with dementia (NPI). No correlation was found in the total group ($r = -0.06$, $p = 0.68$), or in the group of carers with a low baseline sense of competence (SSCQ-score) ($r = -0.09$, $p = 0.72$), indicating that these measures are not interrelated. We also investigated the possible correlations between carers' use of and satisfaction with the support programme and changes in support needs regarding psychological distress (CANE) ($r = 0.25$, $p = 0.41$ and $r = -0.06$, $p = 0.76$) and emotional burden (NPI) ($r = 0.23$, $p = 0.36$ and $r = 0.03$, $p = 0.82$) respectively but no significant correlations were found.

Nursing home admission

After six months of participation, 14.9% (n = 10) of the persons with dementia in the experimental group and 10.9% (n = 7) of the persons with dementia in the control group were admitted to a nursing home. This difference was not statistically significant ($\chi^2 = 0.19$, $p = 0.66$). When making a distinction between the new CO day care centres (E1) and the longer existing ones (E2) on the one hand, and the NH day care centres (C) on the other, the lowest nursing home admission rate (7.7%) was observed in group E2. In group E1, 20.5% had been admitted to a nursing home after six months. However, the differences in admission rates between the two experimental groups and the control group were not statistically significant. We investigated if nursing home admission was correlated to severity of dementia (MMSE; $r = 0.00$, $p = 0.99$) and behaviour and mood problems of the person with dementia (NPI-Q; $r = 0.07$, $p = 0.44$), or sense of competence of the carer at baseline (SSCQ; $r = 0.02$, $p = 0.86$), but found no significant correlations.

Discussion

This study evaluated the effects of CO day care, set up according to the principles of the proven effective Meeting Centers Support Programme model (MCSP) for people with mild to moderately severe dementia and their carers, compared to traditional NH day care on family carer outcomes. Regarding the primary outcome measures (needs and sense of competence) we found that carers in CO day care reported more needs related to psychological distress after six months compared to carers in the NH day care group (medium effect). Further exploration indicated that more needs regarding psychological distress were especially found among carers in newly developed CO day care centres. No differences were found between groups on sense of competence of carers after six months. With regard to the secondary outcome measures (emotional burden, care-related quality of life, objective burden, subjective burden and nursing home admission of the person with dementia), we did not find statistically significant differences between groups. Further explorative analyses pointed out that in carers of the CO day care group who had a low sense of competence at the start of participation in day care, the emotional burden due to behavioural and psychological symptoms of the person

with dementia they cared for decreased over six months, whereas it increased among carers in NH day care (large effect). The carers' need regarding support for psychological distress proved not to be related to this emotional burden, indicating that these are different concepts.

A possible explanation for the expression of more need for support related to psychological distress in the CO day care centres, is that carers may become more aware of their distress when involved in the combined programme, e.g. because the staff gives more attention to the carers' subjective experiences. This awareness and subsequent adverse effect was also found in an online training programme on dementia: the family carers who took this course experienced a decreased sense of competence at the short-term follow-up, possibly caused by increased awareness of the many consequences of dementia and the knowledge and abilities needed to deal with them (Hattink *et al.*, 2015). Moniz-Cook *et al.* (2009) also found negative effects of early combined psychosocial interventions in memory clinics at short-term follow-up (six months), but after 12 to 18 months participants in the interventions appeared to benefit (reduced depression and anxiety in carers) (Moniz-Cook *et al.*, 2009). Furthermore, a review of Cooke *et al.* (2001) also showed delayed improvements on carer outcomes, suggesting a delay in the impact of psychosocial interventions (Cooke *et al.*, 2001). These studies underline the importance of the long-term evaluation of family carer support to gain information on effective support strategies, although other studies did find short-term effects of combined community day care on stress, burden and depression of family carers (Mossello *et al.*, 2008; Zarit *et al.*, 2011; Gaugler *et al.*, 2003).
Our finding that a subgroup of family carers with a low sense of competence at the start of participation in day care in particular benefited from the combined CO day care by experiencing a decline in emotional burden after six months, is in line with a recent review in which several negative caregiver characteristics were found to be related to positive outcomes of psychosocial interventions for carers, such as loneliness, perceived stress, and negative beliefs about the caregiver role (Van Mierlo *et al.*, 2012).

A limitation of our study is the high drop-out rate, which resulted in less statistical power to find potential effects of CO day care compared to NH day care over six months. In all groups, the main reasons for drop-out were nursing home admission or quitting day care.
Another limitation is that we had little information on whether, and how, the support programme was used by carers in the CO day care. Because a characteristic of the CO day cares is that the carers are free to choose if and which support they want to use. We aimed to inventory their actual participation in the different carer support activities by means of the carer survey. Unfortunately, only half of the carers returned this questionnaire. The lack of information on frequency and intensity of support programme utilization, made it difficult to investigate whether the actual received different types of support influenced the effects found in our study. Explorative analyses on our data did not indicate a relationship between the use of the carer support programme and the outcomes on which we found effects.

The study into the added value of the CO day care centres compared to NH day care was performed as part of an implementation study. This implied that the new CO day care centres involved had just made the transition from their traditional NH day care. As a result, especially during the first part of the data collection period, these new day care centres had not yet fully implemented the support programme for the carers, making it less plausible we would find benefits compared to NH day care as found in earlier studies on the Meetings Centers Support Programme (Dröes, 2000, 2004). The majority of centres involved in these effect studies were already operational. We tried to counteract this problem by also recruiting carers of people with dementia who participated in several longer existing CO day care centres, but unfortunately were able to recruit only a small number of participants from these centres.

Taking into account the mentioned limitations, this study should be considered as a first exploration of the added value of CO day care with carer support compared to NH day care. The added value of CO day care for people with dementia was shown in a previous study: people with dementia had less neuropsychiatric symptoms in new CO day care centres and less care needs in longer existing CO day care centres (Van Haeften *et al.*, 2016b). Because combined support for people with dementia and their carers has been proven more effective than single interventions, the transition of nursing home-based day care without carer support to community day care with carer support has the potential to more effectively support people with dementia to live in their own home as long as possible (Brodaty *et al.*, 2003; Dröes *et al.*, 2004; Olazaran *et al.*, 2010). Worldwide, there are many different forms of day cares available and their impact on family carers depends among other things on how the day cares meet the needs of carers (Tretteteig, *et al.*, 2016). An advantage of the CO day cares is that they offer a flexible carer support program. The World Health Organization also stresses the importance of a variety of support facilities, such as respite care and family carer support groups (World Health Organization, 2012). Because CO day cares are offered in more easily accessible locations than traditional NH day care, barriers to using this type of support may be overcome (Van Exel *et al.*, 2006). However, professionals need to be become aware of the effectiveness of these facilities and refer clients to them in a timely manner (Van Haeften-van Dijk *et al.*, 2015). To date the use of CO and NH based day care treatment (besides other forms of day care) is still very low in the Netherlands: only five percent of people with dementia utilize it (Dutch Alzheimer Society, 2014). Other studies also found a low use of day care services among community-dwelling people with dementia, varying from nine to eighteen percent (Beeber *et al.*, 2008; Seematter-Bagnoud *et al.*, 2012; Weber *et al.*, 2011).

Conclusion

This exploratory study on the added value of CO day care compared to NH day care for carers of people with dementia showed that, in general, family carers using CO day care more often expressed a need for support related to psychological distress, although no differences were found between objective burden and subjective burden between the carer groups. This therefore seems to point out that carers using the CO day care with carer support became more aware of their (own) needs for support. Furthermore, in a subgroup of low competent family carers, those who used CO day care with carer support felt less emotionally burdened by the neuropsychiatric symptoms (behaviour and mood problems) of the persons with dementia they cared for than those who used NH day care without a carer support programme. On the other carer outcomes no differences between CO and NH day care were found. In the part of our exploratory study that focused at the impact of CO day care compared to NH day care on persons with dementia we also found positive effects of CO day care (Van Haeften *et al.*, 2016b). Further research in a larger controlled follow-up study, including CO day care centres that have successfully implemented this combined community-based support programme, is therefore recommended to understand the long-term effects for people with dementia and their carers and to draw conclusions on the added value of this combined community-based support programme compared to usual NH day care.

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